

Effectiveness of Community-Based, Nonpharmacological Interventions for Early-Stage Dementia

Conclusions and Recommendations

By: Sandra C. Burgener, Linda L. Buettner, Elizabeth Beattie, and Karen M. Rose

Burgener, S.C., [Buettner, L.L.](#), Beattie, E., & Rose, K.M. (2009). Effectiveness of community-based, nonpharmacological interventions for early-stage dementia: conclusions and recommendations. *Journal of Gerontological Nursing*, 35(3):50-7

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Abstract:

In 2007, a comprehensive review of the extant research on nonpharmacological interventions for persons with early-stage dementia was conducted. More than 150 research reports, centered on six major domains, were included: early-stage support groups, cognitive training and enhancement programs, exercise programs, exemplar programs, health promotion programs, and “other” programs not fitting into previous categories. Theories of neural regeneration and plasticity were most often used to support the tested interventions. Recommendations for practice, research, and health policy are outlined, including evidence-based, nonpharmacological treatment protocols for persons with mild cognitive impairment and early-stage dementia. A tested, community-based, multimodal treatment program is also described. Overall, findings identify well-supported nonpharmacological treatments for persons with early-stage dementia and implications for a national health care agenda to optimize outcomes for this growing population of older adults.

Article:

The effectiveness of, and need for, community-based, nonpharmacological interventions for persons in early-stage dementia has been well documented (Burgener & Dickerson-Putman, 1999; Farina et al., 2006; Moniz-Cook, Agar, Gibson, Win, & Wang, 1998; Newhouse, Niebuhr, Stroud, & Newhouse, 2001; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). Findings from a comprehensive review of the research described in the consensus report to the Alzheimer’s Association (Burgener et al., 2007) support findings from focus groups conducted by the Alzheimer’s Association with persons with early-stage dementia. Findings from both projects indicate the need for support programs and activities designed to help the person manage the disease and “normalize” life.

The two major self-identified unmet needs of persons with early-stage dementia are the need for more community-based programs to support functioning and social needs and assistance with managing the stigma associated with dementia (Alzheimer’s Association, 2008). Other studies have identified the negative impact of social withdrawal, with apathy being the most prominent behavioral symptom in the early disease stages (Clare, 2002; Gilley, Wilson, Bienias, Bennett, & Evans, 2004; Tuokko, MacCourt, & Heath, 1999). The negative outcomes associated with apathy and withdrawal from previous activities include hastened progression of dementia, depression, and increased loss of functional abilities and skills. The conclusions from the consensus report (Burgener et al., 2007) provide substantial support for the effectiveness of nonpharmacological interventions in achieving positive outcomes in the early disease stages. The purpose of this article is to describe these conclusions and make recommendations for actions appropriate to increase the availability of community-based, nonpharmacological interventions.

CONSENSUS REPORT RESULTS

The methods used to obtain the findings for the consensus report are published elsewhere (Burgener, Buettner, et al., 2008), thus will not be repeated here. We will describe the general findings from the comprehensive

review and the global recommendations emanating from the review. The substantial body of research evidence for nonpharmacological interventions for persons in early-stage dementia included more than 150 research reports, summarized in Burgener et al. (2007). The findings are centered on six major domains:

- Early-stage support groups.
- Cognitive training and enhancement programs.
- Exercise programs.
- Exemplar programs.
- Health promotion programs.
- “Other” programs not fitting into previous categories.

Within the health promotion category, research reports fell into areas of sleep management, diet/nutrition, falls prevention, and testing of college courses. In the “other” domain, the research was described within eight categories, including driving safety, volunteer programs, writing interventions, technology-based support programs, art and creative activities, dance therapies, neural stimulation, and narrowly focused programs (e.g., improving cell phone use). Following an overview of the theoretical support for nonpharmacological interventions, recommendations for practice, research, and health policy will be outlined.

THEORETICAL SUPPORT FOR NONPHARMACOLOGICAL INTERVENTIONS

As described in other articles in this special issue, several middle- range theories have been consistently used to support the development of nonpharmacological interventions for persons with dementia. Theories such as the Progressively Lowered Stress Threshold (Hall, 1994; Hall & Buckwalter, 1987), Enablement Model of dementia care (Dawson, Wells, & Kline, 1993), and the Need- Driven Dementia-Compromised Behavior Model (Algase et al., 1996; Kolanowski, 1999) have been developed and tested to increase understanding of variables associated with positive outcomes in persons with dementia. With the exception of the Enablement Model, however, these models have been used primarily to investigate specific behavioral symptoms in persons with dementia; that is, to identify antecedents to behavioral symptoms and develop interventions to positively affect outcomes. Although these models are effective for this stated purpose, focusing primarily on behavioral symptoms may limit researchers in their attempts to more broadly identify interventions to affect a variety of outcomes, including maintenance of function and slowing of disease progression.

Many of the studies reviewed as part of the consensus report (Burgener et al., 2007) were designed to affect multiple outcomes, including cognitive functioning. Theories evolving from the physical sciences were often used to support these studies. Specifically, theories of neurological functioning and regeneration are exciting and promising, as they offer support for interventions designed to assist persons with dementia maintain function and/or slow disease progression. Research using primarily animal models suggests that the brain, despite injury, is capable of extensive reorganization, termed brain plasticity.

The results of animal studies have been reported since the mid-1980s,

EVIDENCE-BASED TREATMENT PROTOCOL: MILD COGNITIVE IMPAIRMENT AND EARLY-STAGE DEMENTIA

A comprehensive diagnostic evaluation is necessary to confirm the diagnosis and rule out other causes of cognitive impairment. Most diagnostic centers use a multidisciplinary team to complete a comprehensive diagnostic examination and ensure the most accurate diagnosis possible. The standard for diagnostic testing includes no less than:

1. History and physical examination.
2. Computed tomography or magnetic resonance imaging scan.
3. Thyroid dysfunction tests, urinalysis, and blood chemistry.
4. Neuropsychological testing.

Mild Cognitive Impairment (MCI)

MCI is defined as (Dubois et al., 2007):

1. A disorder of subjective memory impairment.
2. Objective symptoms are not severe enough to warrant a diagnosis of dementia.
3. Activities of daily living are generally preserved.

Once a confirmed MCI diagnosis has been reached, the following nonpharmacological therapies are recommended to protect cognitive health:

1. Physical exercise, preferably aerobic exercises, if tolerated. If aerobic exercises cannot be tolerated, then exercises that are less-strenuous yet promote strength, balance, and coordination (e.g., tai chi) are recommended.
2. Cognitive therapies, preferably therapies that use cognitive training and rehabilitation or memory rehabilitation as the focus of the training.
3. Comprehensive recreational therapies, including activities such as art, writing, social engagement, and individualized hobbies.
4. Dietary modifications including foods that are rich in antioxidants, such as blueberries, spinach, and strawberries. Replacement of cooking oils (canola, vegetable, corn) with olive oil.

Early-Stage Dementia

Early-stage dementia is defined as:

1. Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) score of 20 or higher.
2. Clinical Dementia Rating scale (Hughes, Berg, Danzinger, Coben, & Martin, 1982) score of 2.0 or lower.
3. Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) score of 2 or lower.

Once a confirmed diagnosis of early-stage dementia has been reached, the nonpharmacological therapies recommended above for MCI are also recommended to promote continuing functioning, assist with independence, and maintain cognitive health. In addition, the following therapies are recommended:

1. Sleep hygiene programs, such as NITE-AD (McCurry, Gibbon, Logsdon, Vitiello, & Teri, 2005).
2. Driving evaluations at least every 6 months, including an on-road test with an experienced driving specialist.
3. Individualized instruction and training in activities to promote independence, such as cell phone use, e-mail use, and computer programs.
4. Electronic reminder and monitoring support programs. (However, costs may be prohibitive for this intervention.)

providing evidence of the brain's capacity to respond structurally to external stimuli. On the basis of animal studies, evidence of the environmental effects on increased neuronal density and synapses per neuron has been found (Black, Sirevaag, & Greenough, 1987; Fillit et al., 2002; Turner & Greenough, 1985). These environmental effects are often termed enriched environments and typically include structured exercise beyond that which is baseline and multiple environmental stimuli, such as sensory stimuli, music, and cognitive tasks. Results indicate that some kinds of physical activity can regulate neurogenesis and synaptic plasticity and improve learning (van Praag, Christie, Sejnowski, & Gage, 1999).

Findings have not been consistent across studies, however. Increased numbers of neurons have been found post-injury in animal studies (rats). However, differences in cell proliferation between study groups (complex environment, exercise, or control) have not been consistently found (Briones, Suh, Hattar, & Wadowska, 2005; Briones, Suh, Jozsa, et al., 2005). In adult primates (macaques), new neurons have been found to develop in three areas of the brain essential to cognitive functioning: prefrontal, inferior temporal, and posterior parietal cortex (Gould, Reeves, Graziano, & Gross, 1999). Collectively, studies using animal models suggest the existence of a use-dependent neuroplasticity in the older brain, although findings are inconsistent (Briones, Suh, Hattar, et al., 2005; Sirevaag, Black, Shafron, & Greenough, 1988; Soffié, Hahn, Terao, & Eclancher, 1999).

In human beings, the production of new neurons has been shown to continue even into later years. On the basis of animal studies and clinical trials in human beings, plasticity theory suggests that both rehabilitative and pharmacological interventions may facilitate neuronal reorganization and recovery of function (Albensi &

Janigro, 2003; Bach-y-Rita, 2003a, 2003b). Within the rehabilitative framework, studies using human beings as participants have begun to test the effectiveness of enriched environments on preservation of neuronal function, including the slowing of cell death inherent in progressive dementia, such as Alzheimer's disease (Bach-y-Rita, 2003a). Robertson and Murre (1999) conducted a review of studies regarding brain plasticity in human beings and concluded that the adult brain can undergo dramatic changes in neural structures, including dendritic and axonal sprouting. Collectively, studies of neural plasticity and regeneration offer new hope for persons with dementia and support the potential effectiveness of nonpharmacological interventions.

RECOMMENDATIONS FOR PRACTICE

Two recommendations from the consensus report (Burgener et al., 2007) have particular relevance for translating findings into practice and increasing the use of evidence-based practice for early stage dementia:

- Recommendation 2.2 (p. 131): That promising interventions be embedded in accessible, community- based settings to minimize the social stigma and “medicalization” of dementia and increase the normalization of persons with early-stage dementia.
- Recommendation 2.5 (p. 132): That implemented programs give high priority to ongoing program continuity (rather than short-term or time-limited programs) to provide sufficient support to maintain older adults with early-stage dementia in their homes at a high level of well-being and functioning.

Following the grading of the evidence, the interventions with the strongest support for positive outcomes include (listed in order of strength of evidence and positive outcomes):

- Multimodal programs using at least two interventions (e.g., exercise and cognitive therapies, exercise rehabilitation or memory rehabilitation as the focus of the training.
- Physical exercise, preferably aerobic exercises, if tolerated. If aerobic exercises cannot be tolerated, then exercises that are less strenuous yet promote strength, balance, and coordination (e.g., tai chi) are recommended.
- Cognitive therapies, preferably those that use cognitive training and rehabilitation or memory rehabilitation as the focus of the training.
- Comprehensive recreational therapies, including activities such as art, writing, social engagement, and individualized hobbies.
- Support group participation.
- Sleep hygiene programs, such as NITE-AD (McCurry, Gibbon, Logsdon, Vitiello, & Teri, 2005).
- Driving evaluations at least every 6 months, including an on-road test with an experienced driving specialist. and behavioral therapies) to affect multiple outcomes, potentially increasing cognitive, physical, and emotional functioning.

Although longitudinal studies were lacking in many areas, some interventions produced positive effects as long as 18 to 24 months following initiation of the intervention, indicating the potential benefits of non-pharmacological therapies in affecting long-term outcomes (Chapman, Weiner, Rackley, Hynan, & Zientz, 2004; Sanglier, Sarazin, & Zinetti, 2004; Teri et al., 2003). On the basis of these findings and limitations of studies that tested short-term interventions (e.g., support groups limited to 10 to 12 sessions), we recommend that therapies not be time limited but instead be continuous for optimal benefit. Also, testing the long-term outcomes from the intervention should be included as a protocol in future research studies.

Findings also suggest that participation with a close family member may increase adherence to the therapies and improve outcomes as well, especially for exercise and cognitive interventions. Optimally, therapies should involve at least two or three interventions. Combined or multi- modal therapies produced the strongest effects, with a combination of exercise and cognitive or recreational therapy producing the most positive, long-term outcomes (Burgener, Buettner, et al., 2008).

Some limitations of the research evidence are apparent, with most domains having few studies that reach the highest level of evidence (A). At this time in the development of theory-driven, empirically tested interventions for this group, it is critical to support the implementation of evidence-based interventions with strong potential to provide benefit to persons in early-stage dementia. To promote this outcome, recommendations for evidence-based, nonpharmacological treatment protocols for both mild cognitive impairment (MCI) and early-stage dementia are provided in the Sidebar on page 52. These protocols reflect the need for promising interventions to be rapidly translated into practice.

A Model for Establishing Community-Based Programs

Findings from this comprehensive review serve as an evidence-based foundation for the development of community-based, nonpharmacological interventions. As noted in the

TABLE

SAMPLE MULTIMODAL PROGRAM CONTINUUM

Name of Program	Disease Stage or Target Clients	Desired Outcome
Routine screening days and referral to geriatrician	Worried about memory	Identify people with memory loss for programs and services
Health Promotion 12-week course	Mild cognitive impairment (MCI) and early-stage dementia	Improved health behaviors, psychosocial well-being, coping
Advanced Cognitive Stimulation class	Worried, MCI, early-stage dementia	Increased cognitive abilities
Advanced Physical Fitness class (modified aerobics, martial arts, pedometer walking)	Worried, MCI, early-stage dementia	Increased physical abilities
Life 101 class	MCI, early-stage dementia, depression	Improved coping, self-expression, creative outlet
Cognitive Stimulation class	Moderate dementia	Improved cognitive abilities
Relaxation classes (chair tai chi, guided imagery, progressive muscle relaxation)	Moderate to severe dementia	Ability to remain centered, calm, relaxed
Pet Encounters class (four stations to improve function)	Early-stage, moderate, or severe dementia	Improved emotional, physical, and social abilities
Exercise for Function class	Moderate to severe dementia, caregivers	Improved physical abilities, better sleep
Recreation Club	Moderate to severe dementia	Improved physical, social, and emotional function and therapeutic respite
Community programs (Simple Pleasures, Pet Partners, wheelchair biking, chair volleyball, support and counseling, school volunteers)	Caregivers, intergenerational groups, volunteers, and others in contact with persons with memory loss	Normalization of dementia in community, recreation, education, and support through generations

Adapted from Buettner and Fitzsimmons (2006).

review, the strongest interventions were multimodal in nature, using at least two different interventions to positively affect multiple outcomes (Buettner, 2006; Buettner & Fitzsimmons, 2006; Burgener, Yang, Gilbert, & Marsh-Yant, 2008; Mahendra & Arkin, 2003; McCurry et al., 2005). Community-based programs can take many forms, with some programs meeting once per week for approximately 4 to 5 hours and others meeting several days per week over a longer time frame (Buettner & Fitzsimmons, 2006). Health professionals with expertise in care of persons with early-stage dementia often lead such programs, because they have the clinical expertise and dedication to effectively offer continuous programs.

Funding for community-based, nonpharmacological programs and services is often obtained through participant fees. Some private support is available specifically for the development and offering of community-based programs, such as the funding available through the Brookdale Foundation (<http://www.brookdalefoundation.org/>). Using multiple sources of funding such as grants, contributions from local community organizations, and participant fees increases the likelihood of a sustainable program.

One successful community-based, multimodal program was developed and tested by Buettner and Fitzsimmons (2006). They designed and tested a continuum of programs that began by identifying older adults with memory problems and filling the gap between diagnosis and early-stage programming with health promotion classes (Table). The full continuum was created to be delivered in naturally occurring retirement areas and was designed to be affiliated with a university, which reduces segregation and stigma. The programs were designed as “classes” for people who were worried about their memory function and extended through the later stages of dementia, providing seamless care for participants. Family members and community members also attend selected programs. The foundation of each program is a core of active recreational activities to stimulate cognitive, physical, and psychosocial well-being.

The Selective Optimization and Compensation (SOC) theory was used as the framework for this program. The SOC model posits that there are three fundamental processes of life management for older adults: selection, optimization, and compensation. The selection process is involved for the participants because they decide which programs fit their needs. Because the programs are individualized with the goal of providing opportunities for physical, cognitive, and psychosocial activities, and because participants are encouraged to do as much independently as possible, skills are optimized. Compensation for deficits participants may have is achieved as staff members create adaptations and teach families how to do the same in the home setting.

RECOMMENDATIONS FOR RESEARCH

Three recommendations for research are of particular relevance, with a complete listing of all research-related recommendations available from Burgener et al. (2007). The recommendations noted in this article include:

- Recommendation 3.2 (p. 132): That funding bodies recognize the need for long-term funding to support continuity in priority intervention programs.
- Recommendation 3.4 (p. 132): That priority is given to studies that are multimodal in nature or with strong theoretical support and that compare interventions head to head, including comparison of nonpharmacological and pharmacological interventions.
- Recommendation 3.6 (p. 133): Those technology-based interventions that show promise be promoted via special funding mechanisms, as they have the unique capacity to affect persons with early-stage dementia who are isolated from treatment options by distance or other factors.

These recommendations reflect the strength of the findings from the consensus report (Burgener et al., 2007) that support the potential widespread effectiveness of multimodal interventions and interventions that are long-term or continuous. Few studies compared pharmacological and nonpharmacological interventions in head-to-head trials. Those few that have made such comparisons tested the effects of a cognitive stimulation intervention against cholinesterase inhibitor therapy. Interestingly, the findings from these studies generally support the effectiveness of nonpharmacological interventions. To support funding priority for testing nonpharmacological interventions, these head-to-head trials need to be conducted for other interventions, such as multimodal interventions and exercise therapies.

Although few studies of technology-based interventions were ranked at the highest level of evidence (A), a high potential exists for technology-based interventions to be used in previously isolated areas. Nonpharmacological interventions and programs are often scant or non-existent in rural and medically underserved areas, but technology-based interventions may be accessible. The potential for long-distance support exists in these kinds of interventions, and the beginning support for their effectiveness increases the potential benefit of these interventions for persons with early-stage dementia.

RECOMMENDATIONS FOR HEALTH POLICY

Three recommendations for a general approach to health policy evolved from the consensus report. These recommendations address the need for a national approach to increasing evidence-based care for persons with early-stage dementia:

- Recommendation 1.1: That associations and organizations committed to support for persons with dementia lead a national information campaign on early-stage dementia to raise awareness of the critical need for services to support dignified, person-centered care and quality of life, including maintenance in the home and community.
- Recommendation 1.2: That the development of community-based early dementia programs become a national health care priority within federal funding agencies and private foundations that support health-related research and the inclusion of these community-based programs as “covered” services in public and private health care insurance providers.
- Recommendation 1.4: That the perspectives of persons with early-stage dementia and those at high risk for developing the disease be given priority in the development of a national agenda for evidence-based early-stage dementia care.

Currently, the “voice” of persons with dementia and those at high risk for developing the disease has not been a significant factor in determining funding priorities or designating “covered” services by public and private health care coverage providers. The recent effort by the Alzheimer’s Association to obtain information and care priorities from persons with early-stage dementia through focus groups is an important step in affirming the importance of this perspective. Using the information gained from such a widespread effort will be the essential “next step” to help ensure appropriate, evidence-based services are developed, disseminated, and supported. The findings from the consensus report (Burgener et al., 2007) may assist with the development of evi-

KEYPOINTS

NONPHARMACOLOGICAL INTERVENTIONS FOR EARLY- STAGE DEMENTIA

Burgener, S.C., Buettner, L.L., Beattie, E., & Rose, K.M. (2009). *Effectiveness of Community-Based, Nonpharmacological Interventions for Early-Stage Dementia: Conclusions and Recommendations*. *Journal of Gerontological Nursing*, 35(3), 50-57.

- 1 Evidence-based nonpharmacological treatment protocols for persons with early-stage dementia are well defined and should be assimilated into clinical practice.
- 2 Multimodal, community-based programs designed for persons in early-stage dementia are offered across the United States and have been shown to produce positive outcomes, including increased cognitive, physical, and social functioning.
- 3 Support from studies using animal models and initial human studies indicate that nonpharmacological interventions can positively affect preservation of neuronal function, including slowing of cell death inherent in progressive dementia.

dence-based nonpharmacological interventions; however, the perspective of persons with early-stage dementia is needed to assure these interventions will meet the varied, person-centered needs of this population.

As evidence-based intervention programs are developed and tested, support from public and private health care insurance providers will be required for widespread dissemination of these interventions. Currently, most community-based, multimodal programs are supported through private pay by participants or through small grants from select foundations. These limited funding sources necessitate that nonpharmacological programs are most often found in areas characterized by a variety of professional health care providers committed to quality dementia care and by a population of users with adequate financial resources. Before programs can be developed in medically underserved areas and in populations of older adults with higher poverty levels, additional continuous funding sources are required. Collective action by all providers and persons affected by dementia is required to bring this agenda to the attention of legislators and health care policy entities at the national level.

CONCLUSIONS

The consensus report provides a relevant source for the development of evidence-based interventions for persons with early-stage dementia. Along with the recommendations outlined in this article, the findings within the consensus report can be used to design optimal community-based programs for persons with early-stage dementia. It is recognized that changes in funding priorities and health care policy are difficult and long term, at best. However, it is our hope that these findings and recommendations will be part of a national agenda to shape research priorities and health care services committed to evidence-based, nonpharmacological programs for persons in early-stage dementia. Early intervention strategies hold the promise of bringing hope to a new generation of recently diagnosed individuals and those who care for them.

These recommendations must be viewed with caution due to the limited number of randomized controlled trials available and due to the methodological limitations identified in the report. Further well-designed trials would help provide more definitive evidence. Individualized interventions that are tailored to the needs of persons with dementia and are interdisciplinary in approach need to be scientifically evaluated in the immediate future. The national research agenda must include these kinds of intervention trials, as there is no cure for dementia on the immediate horizon.

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